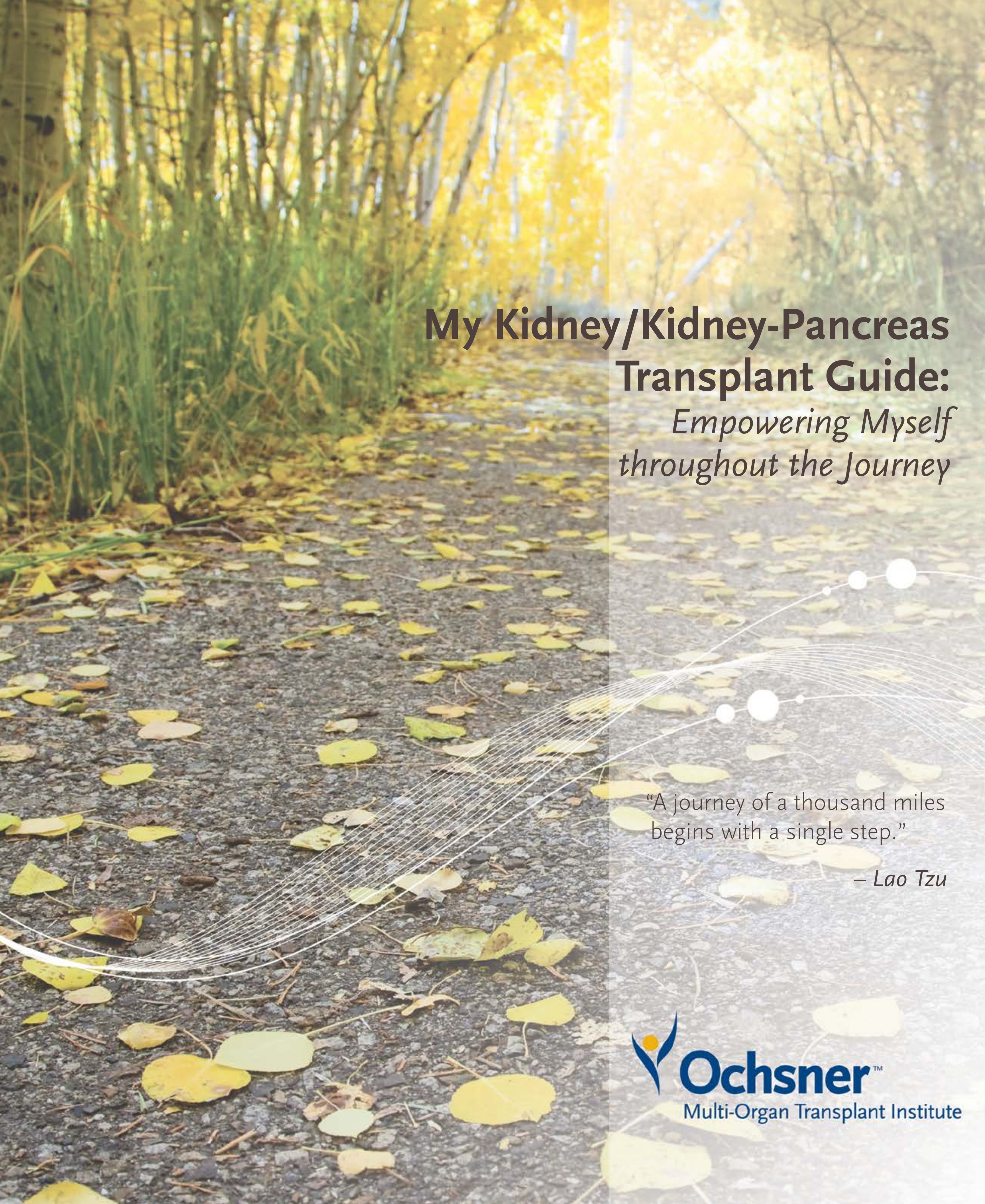


My Kidney/Kidney-Pancreas Transplant Guide:

Empowering Myself throughout the Journey

> "A journey of a thousand miles begins with a single step."
>
> – *Lao Tzu*

Ochsner™
Multi-Organ Transplant Institute

THIS GUIDE IS FOR YOU

This guide is especially designed for you by your Ochsner team to help you along your transplant journey. We value each of you as the unique and special person that you are. We take a personal interest in you and your well-being.

We believe very strongly that we treat more than just kidney and/or pancreas disease. We treat the whole person. We aim to restore the quality of your organ(s), health and life as a whole.

The purpose of your guide is to:

- Give you the transplant information you need
- Encourage you to take the best possible care of yourself
- Prepare you for the lifetime commitments that come with a new organ(s)

Your guide takes you through the stages of the transplant journey.
These stages are covered in nine chapters.
Each chapter goes over important aspects about that stage.

Share your guide
with those close to you.

Refer to your guide often.

Bring your guide
to all your visits.

> "What lies behind us and
> what lies before us are
> tiny matters compared
> to what lies within us."
>
> – *Ralph Waldo Emerson*

USING YOUR GUIDE

Some people like a lot of information. Others like less information.

Some people like all their information at once. Others like their information in small chunks.

YOUR GUIDE IS DESIGNED TO FIT EACH OF THESE DIFFERENT LEARNING NEEDS.

Throughout your guide are these key phrases:

Yes I Can!

- Reminders of important actions you can take as the most valuable player (MVP) of your healthcare team
- Helpful checklists for you to complete during your transplant journey

Helps to Know

- Good information to know or remember

Say What?

- Definitions of words or phrases often used in transplant

Ask Myself*

- Three simple questions and a place to write your answers as a review at the end of each chapter:

1. What do I need to do?
2. What do I need to remember?
3. Why is it important?

*Adapted from AskMe 3™

Thank you

for choosing us as your transplant center.

We are committed to providing you with excellent care.

We want the best for you!

NOTES

Blank pages for you to write more notes at the end of this guide

Many transplant staff members helped put together this guide.
Our transplant patients and their caregivers also gave us great ideas.
May you benefit from the wisdom and compassion of everyone who contributed.

TABLE OF CONTENTS

THE NEWS:
Finding out I need a transplant

I need a transplant?!?
What exactly does this mean?
Am I going to be OK?
Is it going to cost a lot of money?
Will I be able to live longer?
Is it going to hurt?

These and many other questions may be swirling through your head. Finding out you need a transplant can be a time of mixed feelings – from fear about the unknowns to excitement over new beginnings – and every emotion in between!

So before we go on, take a deep breath (or two), pause and remember: We at Ochsner are here for you and your family as you go through the transplant journey. The transplant process can be physically, emotionally and mentally challenging. There is so much to plan for and remember.

The really good news: Our expert transplant team has successfully helped thousands of patients through this process. So let our expertise guide you.

"It always seems impossible
until it's done."

– *Nelson Mandela*

LIFELONG BENEFITS

A transplant can have lifelong benefits. Transplant can be a great choice for treating kidney disease and diabetes.

Data shows

- More people get transplants every year
- More people with kidney and/or pancreas transplants are living longer

- People with kidney transplants are not just free from dialysis. They often:
    - Have less medical complications than dialysis patients
    - Live longer than dialysis patients

HELPS
to know

It is easy to feel as if you are not in control when you are sick. What you can always do during your transplant journey:

- Partner with your transplant team.
- Be involved in your healthcare.
- Agree on the best healthcare plan for you.
- Stick to the plan you and your transplant team agree is best for you!

Carefully following your healthcare plan helps protect your health before and after transplant.

YOUR TRANSPLANT TEAM

There are 2 key members of your transplant team

1 YOU – Most Valuable Player (MVP)!

Why are you the MVP (Most Valuable Player) of your transplant team? Because your actions impact your health from now until after transplant. Patients who actively take part in their care and carefully follow their treatment plan are the patients who usually feel and do better.

2 Your Caregivers

Choosing your caregivers is a very important decision. These are the people available at all times to help you before, during and after transplant. Your caregivers may be a spouse, partner, parent, family member or close friend, or some combination of these persons.

I am my transplant team's
MVP
(Most Valuable Player)

MVP:
____
(YOUR NAME HERE)

THE REST OF YOUR TRANSPLANT TEAM

The transplant process is truly a team effort: You give it your all and we do the same! You and your transplant team work together as you go through the transplant process. Some team members you see often. You may see others less often. All team members are here to help you!

Let us take a closer look at what each team member does:

- **TRANSPLANT SURGEON**

  Doctor trained in transplant surgery. Follows you before, during and after your transplant.

- **TRANSPLANT NEPHROLOGIST**

  Doctor trained in treating medical conditions related to kidney disease. Manages your care before, during and after transplant.

- **ADVANCED PRACTICE PROVIDER**

  Nurse practitioner or physician assistant skilled in the treatment of kidney disease and diabetes. Works closely with your doctors to assess and treat you before and after transplant.

- **NURSE COORDINATOR**

  Nurse skilled in kidney disease and diabetes. Coordinates all aspects of your care before, during and after your transplant.

- **HOSPITAL NURSE**

  Hospital staff nurse who helps you while you are in the hospital.

- **SOCIAL WORKER**

  Helps you and your family handle the changes in your life as a transplant patient. Listens to your concerns. Gives support. Tells you about helpful resources.

- **FINANCIAL COORDINATOR**

  Helps you understand your transplant costs and insurance coverage.

- **PHARMACIST**

  Helps you understand the medicines you take before and after transplant.

- **DIETITIAN**

  Helps you understand the right foods to eat before and after transplant.

- **SCHEDULER**

  Makes your appointments. Lets you know when and where to go for your visits.

- **PRESCRIPTION ASSISTANCE PROGRAM (PAP) COORDINATOR**

  Helps you sign up for programs that may help pay for your medicines, if you qualify.

- **MEDICAL/SURGICAL FELLOWS AND RESIDENTS**

  Doctors-in-training who work closely with the surgeons and nephrologists to assess and treat you.

- **OTHER HEALTHCARE STAFF MEMBERS**

  Some team members work behind the scenes. You may not meet them in person. Other healthcare staff members are added to your team to meet your specific needs. All of them are working together to make sure you get the best, complete care!

MY ROLE AS MVP

YES I CAN!

WHAT I ALWAYS WANT TO REMEMBER

☐ Do my part as my transplant team's MVP(Most Valuable Player).
☐ Follow the healthcare plan that my transplant team and I agree is best for me.
☐ Include my primary caregivers in all aspects of my care.
☐ Learn all I can about my illness and transplant.
☐ Keep a transplant notebook with all my information.
☐ Keep a calendar with all my transplant-related appointments.

WHAT MY TRANSPLANT TEAM NEEDS FROM ME SO THEY CAN DO THEIR PART

☐ Share all I can about my health in a timely manner.
☐ Show up for all my appointments, labs and tests.
☐ Bring my caregivers to my appointments – two (or more) heads are better than one!
☐ Take my medicines exactly as instructed.
☐ Never let my medicines run out! Refill my medicines on time, every time.
☐ Ask questions when I am not sure.

OTHER ACTIONS I CAN TAKE TO HELP MYSELF

☐ Talk openly about any fears or doubts I have.
☐ Take it one day at a time, one visit at a time.
☐ Keep in mind that this can be an emotional time.
☐ Stay connected to others.
☐ Stay as active and healthy as possible.
☐ Be honest with my transplant team. The more honest I am, the better they can help me.

> “Life isn’t about waiting for the storm to pass. It’s about learning to dance in the rain.”
> – *Vivian Greene*

SAY *what?*

I have heard my healthcare team say how important it is to ***adhere*** to the treatment they give me. But what exactly does ***adhere*** mean?

Adhere to treatment means to follow the instructions of the healthcare team. We partner with you to agree on the best healthcare plan for you. Your part is to stick to the plan once we all agree – this is what ***adhere to treatment*** looks like in action!

PATIENT – TRANSPLANT TEAM COVENANT

The Patient-Transplant Team Covenant is a reminder of the important relationship between patients and those who provide healthcare. Respect, trust and partnership between patients and healthcare team members set the foundation for healing.

The partnership between you and your transplant team starts with your first visit. It continues over many years, both in the clinic and hospital. The Patient-Transplant Team Covenant reminds us of this partnership's key guidelines.

Patient-Transplant Team
COVENANT

As the ***Transplant Team*** *and partner in your healthcare, we commit to always:*

As a ***Patient*** *and partner in my healthcare, I commit to always:*

VALUE YOU AS A PERSON

- Recognize you as a whole person.
- Respect your dignity, values and beliefs.
- Keep your information private unless you give us permission to share.
- Carefully listen to what you have to say.

VALUE YOU AS PEOPLE

- Recognize you as people committed to my well-being.
- Respect your expertise and experience.
- Be very clear about what information is okay to share with others.
- Carefully listen to what you have to say.

RESPECT

TELL YOU THE TRUTH WITH COMPASSION

- Help you feel comfortable sharing your doubts and fears.
- Be honest about your health conditions and how you respond to treatment.
- Tell you about your medical condition in a timely manner.

TELL YOU THE TRUTH WITH CONFIDENCE

- Be able to talk about my doubts and fears with you.
- Be truthful about my health, treatments and how I am following your instructions.
- Tell you all I can about my health in a timely manner.

TRUST

INCLUDE YOU AS AN ACTIVE TRANSPLANT TEAM MEMBER

- Partner with you to agree on your best healthcare plan.
- Coordinate with all who provide you with healthcare.
- Answer your questions as best we can.
- Include your caregivers as part of your transplant team.

BE AN ACTIVE MEMBER OF MY TRANSPLANT TEAM

- Partner with you on the healthcare plan I agree to follow.
- Tell you about everyone who provides me with healthcare.
- Ask you right away when anything is not clear to me.
- Include my caregivers as part of my transplant team. Bring a caregiver to all my visits.

PARTNERSHIP

Ochsner™
Multi-Organ Transplant Institute

ASK
myself

1.

What do I need to do?

2.

What do I need to remember?

3.

Why is it important?

THE BASICS:

Let us backtrack for a moment

YOUR KIDNEYS

**Most people have two kidneys.
Your kidneys lie in your back.**

WHY YOUR KIDNEYS ARE IMPORTANT

Your kidneys do some of your body's most important jobs.

Your kidneys help:

1. Clean your blood
2. Get rid of waste by making urine
3. Balance fluids and minerals in your body
4. Control blood pressure
5. Keep bones strong
6. Work with your bone marrow to make red blood cells

KIDNEY DISEASE

Kidney failure is when your kidneys do not work well. They may be too damaged from illness or injury.

Waste and extra fluid can build up when your kidneys do not work well. This can harm your body.

End-Stage Renal Disease (ESRD) is when your kidneys cannot do their job anymore. ESRD is permanent. It cannot be reversed. ESRD can happen when kidney disease has not:

- Been diagnosed early enough
- Been treated early enough
- Improved with present treatment

You need treatment to stay alive when your kidneys stop working. Treatment options for ESRD include:

- Dialysis
    - Hemodialysis
    - Peritoneal dialysis
- Kidney transplant

Both dialysis and transplant have side effects. It is important to know about all treatment options. You can then make the best treatment choice for ***you.***

> {"Your present circumstances don't determine where you can go;
> they merely determine where you start."}
>
> – *Nido Qubein*

HELPS *to know*

You may think you are "cured" once you have a transplant. Transplant is not a *cure*. It is a *treatment* because ongoing care is needed after transplant to keep your new organ(s) healthy.

Most transplant patients can lead more normal lives after transplant. As long as you have a new organ(s), you need to:

- Take medicines every day
- Have regular follow-up care
- Follow your healthcare team's advice
- Take care of your body

Transplant is not a *cure*.
It is a *treatment*.

WHAT YOU MAY SEE OR FEEL WHEN YOU HAVE KIDNEY DISEASE

- Fluid buildup in your body
    - Puffy face
    - Swollen hands, feet
- Changes when you urinate
    - How much
    - How often
    - Pain
    - Hard time
- Shortness of breath
- Confusion
- Tiredness
- Weight loss due to changes in taste and appetite
- Abnormal blood or urine test results

NOTE: You may have no symptoms until you have had kidney disease for awhile.

CAUSES OF CHRONIC KIDNEY DISEASE

Certain medical conditions can lead to chronic kidney disease. These include medical conditions that:

- You are born with
- Run in your family
- Have been attacking your kidneys for a long time

  Some examples are:
    - Diabetes
    - High blood pressure
    - Infection
    - Cysts
    - Kidney stones

KIDNEY TRANSPLANTS

Kidney transplant is the surgery where the transplanted kidney provides kidney function instead of the sick kidney. This new, healthy kidney can be donated from a person who has died or from someone who is still living. A kidney transplant is needed when your kidney fails to do its job like it should.

DECEASED DONOR KIDNEY TRANSPLANT

Deceased donor kidney transplant is a transplant using the kidney from someone who has died. Most donated kidneys come from people who recently died. Deceased donor kidneys are matched with people on a national transplant waiting list. The people on this list have been evaluated. They are considered to be good kidney transplant candidates.

LIVING DONOR KIDNEY TRANSPLANT

Living donor kidney transplant is a transplant using a living person's kidney. There are not enough deceased donor kidneys available on the national waiting list for the people who need them. One option for people is a transplant that uses a kidney from someone who is still alive.

SAY *what?*

Organ is a part of your body that has a specific job or function. Some examples of organs are your kidneys, pancreas, heart, liver and lungs.

YOUR PANCREAS

Your pancreas lies in your belly behind your stomach.

WHY YOUR PANCREAS IS IMPORTANT

Your pancreas has two main jobs. It helps you:

1. Digest food
2. Control your blood sugars

> “Worry does not empty tomorrow of its sorrow. It empties today of its strength.”
>
> – *Corrie Ten Boom*

SAY *what?*

Insulin is the hormone that controls your blood sugars.

YOUR PANCREAS AND DIABETES

Your pancreas does not work like it should when you have diabetes. Diabetes can cause problems over time. You might:

- Not be able to tell when your blood sugar is low. You may faint or have seizures as a result.
- Not be able to control your blood sugar levels even though you are carefully following your healthcare plan.
- Have kidneys that do not work well (kidney failure) due to diabetes.

TYPES OF DIABETES

There are two types of diabetes

- Type 1 diabetes: Your pancreas cannot make insulin.
- Type 2 diabetes: Your pancreas makes insulin, but your body does not respond to it correctly.

WHAT YOU MAY SEE OR FEEL WHEN YOU HAVE DIABETES

- Urinate more often
- More thirsty
- More hungry – even though you eat well
- More tired
- Blurry vision
- Cuts/bruises that heal slowly
- Weight loss – even though you are eating more (type 1 diabetes)
- Tingling, pain or numbness in your hands, feet
- No noticed symptoms

KIDNEY-PANCREAS TRANSPLANTS

Kidney-pancreas transplant is the surgery where the transplanted kidney-pancreas replace the function of the sick kidney-pancreas in someone with both kidney failure and diabetes. The new kidney-pancreas are transplanted at the same time with organs donated by a deceased donor.

HELPS *to know*

A new, healthier organ replaces the function of your sick organ when you have a transplant. Your body looks at this new organ you got from someone else as a foreign object that it wants to fight against. The only way for your body to accept this new organ as a part of you is to give you medicines.

You can easily and quickly lose your new organ(s) if you do not take these medicines *exactly* as instructed. That is why it is so important for you to be *super* careful with your medicines and healthcare plan after transplant!

Your original organ(s) remains in place when you get a transplant. The original organ(s) is only removed if it is causing problems.

MORE ON TRANSPLANT CANDIDATES

We look at certain factors to decide if transplant is or is not a good option. Persons are considered possible candidates for transplant when:

Kidney	Pancreas
• End-stage renal disease **OR** • Advanced renal failure – GFR (Glomerular Filtration Rate) less than 20 ml/min	• Type 1 diabetes **OR** • Type 2 diabetes

There are other reasons why a person may or may not be a good transplant candidate. Let us look more closely at these reasons:

REASONS A PERSON IS NOT A GOOD TRANSPLANT CANDIDATE

Kidney or Pancreas

You ***are not*** a candidate if you:

1. Have a BMI (Body Mass Index) that is too high. Your BMI is too high if it is higher than:
    - 40 for kidney transplant
    - 30 for pancreas transplant (type 1 diabetes on insulin)
    - 28 for pancreas transplant (type 2 diabetes on insulin)
2. Have cancer
3. Have an infection
4. Smoke (if you need both a kidney and pancreas)

REASONS A PERSON MAY NOT BE A GOOD TRANSPLANT CANDIDATE

Kidney or Pancreas

You ***may not*** be a candidate if you:

1. Are 65 years old or older with several advanced diseases
2. Are at high risk for medical or surgical complications
3. Have other diseases that may affect your health. Some examples are:
    - Heart disease or failure that cannot improve with treatment
    - Severe lung disease
    - Diabetes with severe vascular disease
4. Have a mental health condition that stops you from taking care of your new organ(s). For example, when you:
    - Are not able to understand your illness
    - Cannot make good decisions about your treatment
    - Have an intellectual developmental delay that limits how well you can take care of yourself
    - Are at risk of harming yourself or others
    - Use alcohol or drugs in a way that hurts your new organ(s) and/or health
5. Use tobacco and have severe heart or vascular disease
6. Have unrealistic expectations about transplant risks and/or benefits
7. Do not follow recommended medical care even though you have been told what can happen if you do not do so. Your medical care includes dialysis appointments, medicines, office visits and labs.
8. Do not have a good support system so you can follow recommended medical care after transplant. This includes medicines, office visits and labs after transplant.
9. Have a wound that does not heal

SAY *what?*

BMI (Body Mass Index) is a number that measures body fat based on a person's weight and height.

GFR is short for ***glomerular filtration rate***. The GFR checks how much blood passes through the glomeruli. ***Glomeruli*** are tiny filters in the kidneys that remove waste from the blood.

GFR is the best test to:

- Measure how well your kidneys are working
- Know your stage of kidney disease

Vascular disease is a disease of the blood vessels that could affect how the kidneys and/or pancreas receive blood flow and function.

LIVING DONOR KIDNEY TRANSPLANT

Living donor kidney transplant is a transplant using a living person's kidney. There are not enough deceased donor kidneys available on the national waiting list for the people who need them. One option for people is a transplant that uses a kidney from someone who is still alive.

Most people are born with two kidneys. This means one of the two kidneys can be taken out and put into another person's body. The donor's kidney adapts to make up for having one kidney.

Living kidney donation is safe. Donating a kidney does not affect how long a donor lives. A donor is at no greater risk for kidney failure than an average person. Adult family and friends can be considered as living donors.

People ***can*** donate if

- They are at least 18 years old
- They are in overall good health
- Their blood type is the right type for the person needing a new kidney
- Donating their kidney is something they really want to do

People ***cannot*** donate if they

- Are severely overweight (BMI over 33)
- Have cancer
- Use illegal drugs or abuse drugs
- Have diabetes
- Have active infections
- Are pregnant

People ***may*** be able to donate if they have

- High blood pressure that is well controlled
- Kidney stones

ADVANTAGES OF A LIVING DONOR KIDNEY TRANSPLANT

1. HIGH QUALITY NEW KIDNEY

We know more about a living donor's past and present health. This means we are better able to make sure the donor's kidney works well for you. Kidneys from living donors usually work better for a longer time.

2. TIMELY TRANSPLANT FOR PATIENTS NOT ON DIALYSIS

Your living donor transplant can be done before you get sicker or before you begin dialysis. This means you can have the transplant done at the best time for you.

3. SHORTER WAIT TIME

You do not have to wait for three to five years on a list when you have a living donor. This means you may be in better health when you have your transplant.

4. TIME TO PLAN

You have more time to plan with a living donor. This means your transplant can be done when you and your donor are in the best health possible.

5. UNIQUE GIFT FROM THE LIVING DONOR

This is a special time for the donor to offer the gift of better health to the person needing a new kidney.

STEPS TO BE A LIVING DONOR

1. INTERVIEW

- Donor must call to begin the process.
- Donor's information is taken over the phone. This includes getting the donor's medical history.

2. EVALUATION

- Blood tests are done to know if the donor's kidney is a match for you. This can be done in the donor's hometown.
- Tests are done to make sure the donor is healthy and that their kidneys work well. This must be done at Ochsner's transplant center in New Orleans, LA.
- Test results are reviewed. It is decided if the person can donate.

3. SURGERY

- Surgery is scheduled after the donor is approved.
- Surgery is done laparoscopically. It is minimally invasive. This lets the donor heal more quickly.
- Surgery lasts about three to four hours.
- Donor stays in the hospital for 24 hours.
- Donors can restart most regular activities within two to four weeks.

The insurance of the person needing the kidney pays for the donor's:

- Testing
- Surgery
- Hospital stay
- Medical visits for the first month after surgery

NOTE: *Travel and time off from work are not paid for by insurance.*

KIDNEY PAIRED DONATION (KPD)

KPD is a national kidney swap program. This is an option if your donor:

- Is not a match for you
- Has a different blood type than you need

HOW KIDNEY PAIRED DONATION WORKS

- Your donor offers a kidney to someone in the country waiting for a kidney transplant. In return, you get a kidney that matches with you.
- Your donor's evaluation and surgery are done at Ochsner. (See Steps to Be a Living Donor.)
- Your donor's kidney is sent to the transplant center where the person getting that kidney is being transplanted.
- The kidney that matches with you is shipped to Ochsner for your transplant.

Anyone interested in being tested as a living kidney donor:

Call 504-842-3925.

Ask to speak with the Living Donor Kidney Coordinator.

ASK *myself*

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

THE FIRST STEP:

It starts with my work-up

YOUR TRANSPLANT WORK-UP

We know you have a sick organ(s). Now we want to be sure you are a good transplant candidate. We call this your *transplant work-up* or evaluation – just a fancy word for how we decide if a transplant is right for you.

We look at three areas to decide if transplant is right for you

1 MEDICAL

Make sure you are healthy enough for the transplant surgery and life after transplant.

- We collect important information about your health from several medical tests and visits.
- We look more closely at your sick organ(s) and your body.

2 PSYCHOLOGICAL AND SOCIAL

Make sure you are prepared in your personal life for the lifetime commitments needed for a transplant.

- We collect important information about your past and present life.
- We look more closely at your life to be sure you:
    - Are mentally and emotionally prepared for life with a transplant
    - Have enough people to care for you before and after transplant

3 FINANCIAL

Make sure you are financially ready for the lifetime costs of a transplant.

- We give you important information about costs before and after transplant.
- We look more closely at your insurance and finances to be sure you can pay your transplant costs.

MEDICAL EXAM,TESTS AND VISITS

PHYSICAL EXAM/MEDICAL HISTORY

Your physical exam gives your doctor an overall picture of your medical conditions. Your doctor gets a complete medical and surgical history from you. This history helps decide what other tests need to be done.

MEDICAL TESTS

Every person is different. Your specific medical tests and visits are unique to you. You are told if you need extra tests or exams.

Some common tests in the work-up are:

TYPE OF TEST	REASON FOR THE TEST
Blood work	See how well your overall health is
Chest x-ray	Make sure your lungs are fine
Electrocardiogram (EKG)/Echocardiogram	See how well your heart works
Cardiac stress test	See how well blood flows in your heart
Colonoscopy	Check for colon cancer
Mammogram	Check for breast cancer
Pap smear	Check for cervical cancer
Kidney/Belly ultrasound	Make sure your kidneys/other organs are fine
Ultrasound of blood vessels	See how well blood flows in your vessels. New kidney and/or pancreas is connected to these blood vessels
Shots	Protect you from infectious diseases (like flu, pneumonia)

YOU MAY SEE MORE DOCTORS:

Cardiologist: Checks to make sure your heart is in good condition.

Infectious Disease Doctor: Checks to make sure you do not have certain infections and your shots are up-to-date.

Gynecologist: For the ladies only.

Psychiatrist: Looks at how mentally and emotionally ready you are for a transplant.

Dentist: Checks to make sure your teeth and gums are healthy. Your dentist needs to check you every year while you wait for a transplant.

SPECIFIC BLOOD TESTS THAT ARE ALSO DONE

VIRAL TESTING

Shows if you have been exposed to certain viruses:

- Hepatitis
- Chicken pox
- Cytomegalovirus (CMV)
- Epstein-Barr (EBV)
- HIV/AIDS

BLOOD TYPING

Tells us your blood type. Every person has a blood type A, B, AB or O. You and your donor's blood type do not need to be the same type. You and your donor's blood type do need to be compatible for you to receive that donor's organ(s).

TISSUE TYPING

Tissue type is used to help match a kidney and/or pancreas to you.

PANEL REACTIVE ANTIBODY (PRA)

Measures your body's immune system activity from 0-100%. The PRA percentage is higher when your body is making more antibodies. This means your immune system activity is higher.

Reasons why your immune system may be higher:

- Blood transfusion
- Pregnancy
- Previous transplant
- Current infection

SAY *what?*

Antibody is a protein your body makes to fight disease. Antibodies can affect your transplanted organ(s).

HELPS *to know*

Let us know if you have had any of these tests done with your own doctor in the last year. Tests done within the last year do not need to be repeated.

You can:
- Bring your test results to your next appointment with us

OR
- Ask your doctor to fax the results to your transplant coordinator

Arrive on time for all your appointments. You may miss other appointments that follow or be rescheduled if you are late. This can slow down your work-up.

Bring any medicines or insulin you need during the day. You are scheduled for several tests and visits on each day of your work-up. You are here for most of the day.

These are full and busy days. There is time for lunch in your schedule. You may bring your lunch and snacks. You can also buy food at one of our restaurants.

AFTER YOUR WORK-UP IS COMPLETE

You have:

- Met with transplant staff members to look more closely at your medical, psychological, social and financial situation
- Completed all needed medical testing
- Confirmed who your primary caregivers are
- Submitted any needed paperwork

You have finished your work-up. Now the transplant staff meets. They go over your medical, psychological, social and financial information.

The transplant staff may decide to either:

1. List you for transplant now. OR
2. Wait until they have more information from you before they decide. OR
3. Not list you because transplant is not the best option for you at this time.

The transplant staff talks with you once they have met to review your work-up information. You and the transplant staff together agree on your next steps.

You, your doctor and your dialysis unit receive a letter about your transplant. This letter is sent out within 10 days of the transplant staff's decision.

My work-up is the time for me to:

Get all the information I need

Learn all I can about my medical condition

Ask all my questions

Speak up about any concerns

Know the risks and benefits of my transplant surgery

Plan ahead for my financial, care taking and medical needs

ASK *myself*

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

THE PSYCHOLOGICAL AND SOCIAL SIDE OF TRANSPLANT:

A closer look at my life

You and your social worker meet to:

- Help you be prepared for the lifetime commitments needed for a transplant
- Confirm your caregiver plan
- Talk about how you are dealing with life changes as a transplant patient
- Identify any needs you might have
- Connect you with helpful resources
- Provide support

Bring Your Primary Caregivers!

Your social worker needs to give and get certain information directly from your caregivers. Your caregivers can also help you better remember what you talked about with your social worker – two (or more) heads are better than one!

> "In the middle of every difficulty,
> lies opportunity."
> – *Albert Einstein*

TAKING A CLOSER LOOK AT YOUR LIFE

A transplant affects your whole life, both before and after transplant surgery. We want to make sure you are as ready as possible.

Being ready for a transplant involves:

YOU AS A PERSON

We want you to be mentally and emotionally prepared for life with a transplant.

YOUR CAREGIVER SUPPORT

We want you to have arranged for enough people to care for you before and after transplant.

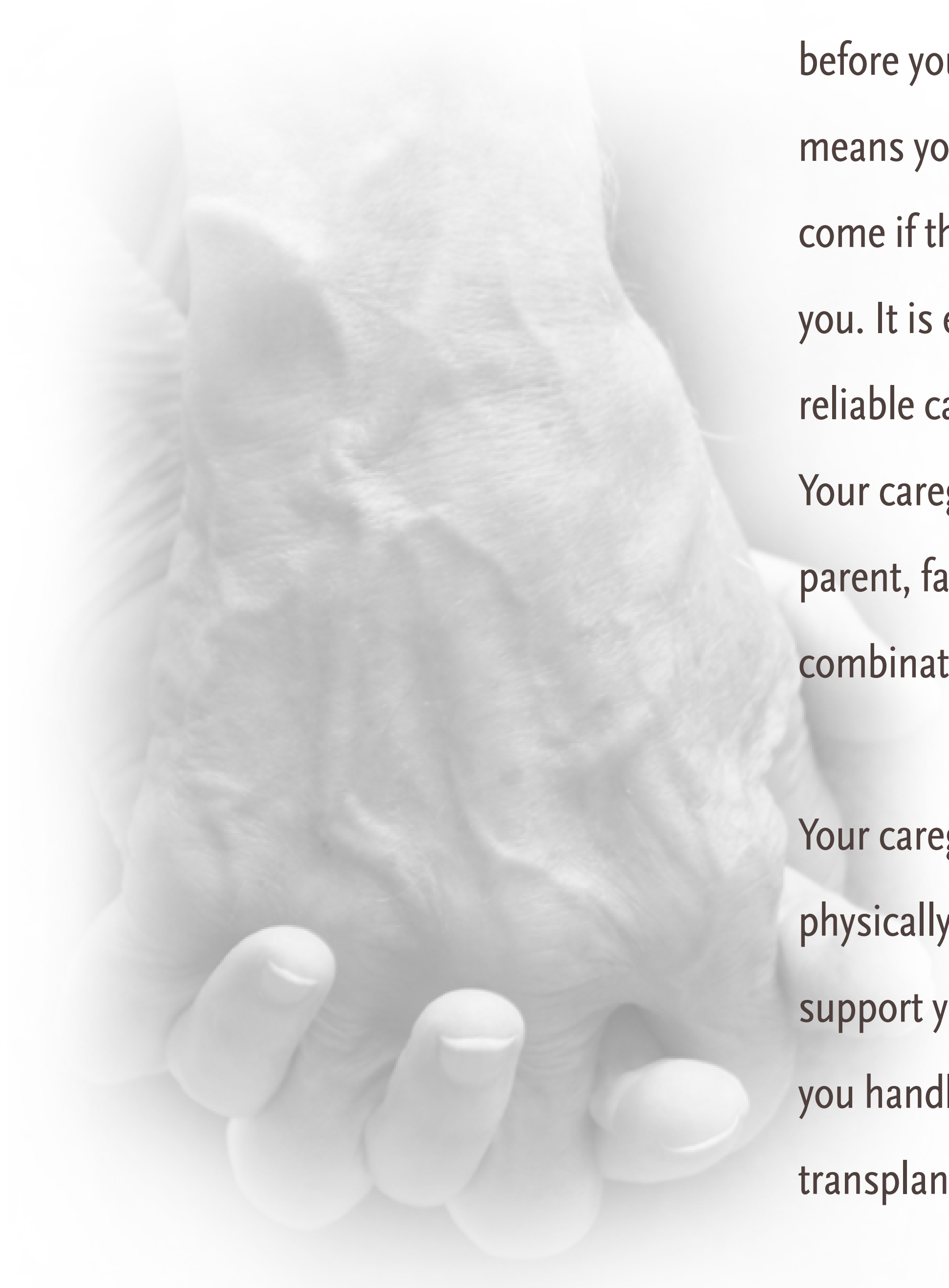
YOUR DAILY LIFE

We want you to have arranged for the financial and other resources to best care for yourself before and after transplant.

We are here to help you. Be open with us. The information we get helps us best help you along your transplant journey.

CHOOSING YOUR CAREGIVERS

Choosing your caregivers is a very important decision as a transplant patient. Your caregivers are the people available to you at all times to help you before, during and after transplant.



You must have arranged for at least one reliable person as your primary caregiver before you can be listed for transplant. This means you may need a second person to come if the primary caregiver cannot be with you. It is even better if you have a group of reliable caregivers available to care for you. Your caregivers may be a spouse, partner, parent, family member or friend, or some combination of these persons.

Your caregivers help you do things that you physically cannot do as you get better. They support you mentally and emotionally as you handle the ups and downs of the transplant process.

Your caregivers agree to:

- Go with you to your appointments and education sessions before transplant
- Help you with transportation for your medical visits and labs before and after transplant
- Be available to you as needed while you are in the hospital for your transplant
- Be with you for all teaching in the hospital
- Help you for as long as needed – until your doctor says you can be left alone
- Know what symptoms to look for before and after transplant
- Tell the transplant team right away if you have any concerns or health changes before and after transplant
- Learn your medicines. Make sure you are taking them the right way – especially important after transplant

CAREGIVER SUPPORT MEANS

PHYSICAL
support when you feel weak or need help

EMOTIONAL
support when you feel discouraged or sick

SPIRITUAL
support when you need someone to pick up your spirits

TENDER-LOVING CARE (TLC)
from a caring family member or friend as you heal

Your caregivers play a major role before, during and especially after your transplant. This personal help is so important that you can only be transplanted if you have reliable caregivers. Please note: Home health care is not enough to count as a caregiver.

HELPS *to know*

Ochsner's transplant team has monthly support groups for patients and caregivers. These groups are another way to get extra support. We encourage you, your family and friends to attend support groups before and after transplant.

Some people in the group have been transplanted. Others are waiting for a transplant. It is a great time to connect and share with people who can relate to what you are going through.

> "Friendship is born at that moment when one person says to another, 'What! You too? I thought I was the only one."
>
> – *C.S. Lewis*

SUBSTANCE ABUSE

Simply put: Take only what your doctor says to take.

Ask your doctor if you wish to take other medicines or any alternative medicines.

IT IS IMPORTANT FOR YOUR OVERALL HEALTH AND THE HEALTH OF YOUR NEW ORGAN(S) TO KNOW:

- **Alcohol and illegal/street drugs**
  Alcohol and drugs can interfere with your medicines and hurt your transplanted organ(s). Alcohol and drugs also affect your health.

- **Tobacco – smoking, dipping or chewing**
  Tobacco can damage your body, especially your lungs and blood vessels:
  - Smokers are more likely to get pneumonias that are harder to treat than for non-smokers.
  - Damaged blood vessels increase your risk of stroke, heart attacks, hardening of the arteries and even kidney damage.

All patients can be asked to take random alcohol/drug screenings as needed. A positive alcohol or illegal/street drug screen may affect if and when you can get a transplant.

Be honest with us if you have any trouble staying off alcohol, illegal/street drugs or tobacco. Many community resources are available to help you. Your transplant social worker is here to help connect you with these resources. Your transplant team may ask you to get professional help to be alcohol or drug-free.

MY AFTER-TRANSPLANT PLAN

YES I CAN!

PRIMARY CAREGIVERS

Who will care for me after I leave the hospital?

☐ Family member
☐ Friend
☐ Other

My caregivers ____

____

PLACE TO STAY

Where will I stay after I leave the hospital?

- ☐ Short-term housing
    - ☐ Family
    - ☐ Friends
    - ☐ Hotel
    - ☐ Apartment
- ☐ Long-term housing
    - ☐ Your home
    - ☐ Family
    - ☐ Friends
    - ☐ Other

My place to stay ____

____

> "The person who removes a mountain begins by carrying away small stones."
> – *Anonymous*

WAY TO PAY FOR MEDICINES

How and where will I buy my medicines after I leave the hospital?

☐ How: Financial plan
    ☐ Insurance (private insurance, Medicare, Medicaid)
    ☐ Cash
    ☐ Full-time or part-time work
    ☐ Fundraising
    ☐ Other
☐ Where: Pharmacy (name and phone number)

My medicine information ______________________________

____

FUNDS

How will I pay for all my transplant-related expenses after I leave the hospital?

    ☐ Insurance (private insurance, Medicare, Medicaid)
    ☐ Cash
    ☐ Full-time or part-time work
    ☐ Fundraising
    ☐ Other

My funds ____

____

TRANSPORTATION

How will I get around after I leave the hospital?

    ☐ Family member's car
    ☐ Friend's car
    ☐ Taxi
    ☐ Bus
    ☐ Other

My transportation ____

HELPS *to know*

Kidney Only Patients
You are moved to the Transplant Stepdown Unit (TSU) after surgery. TSU is a floor especially for adult transplant patients. Caregivers are encouraged to stay with you overnight in your TSU room.

Kidney-Pancreas Patients
You are first taken to the Intensive Care Unit (ICU) after your surgery. You are moved to TSU once you are medically cleared. ICU has visiting restrictions. Only one caregiver can stay overnight with you in your ICU room.

Now is the time to plan where your caregivers will stay while you are in:

1. TSU
2. ICU

DRIVING AFTER TRANSPLANT

You can only drive when your transplant team says it is okay. Plan on not driving for about four to six weeks after transplant if you are off your pain medicine.

YOU NEED TRANSPORTATION FOR:

- Day you leave the hospital after transplant
- Follow-up medical visits, labs and tests

Someone needs to be with you even if you take a taxi, bus or other public transportation. Ochsner cannot provide regular transportation. We can help you and your caregiver locate a taxi service to take you home from Ochsner if needed.

ASK *myself*

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

THE FINANCIAL SIDE OF TRANSPLANT:

Planning for my needs

You and your financial coordinator meet to:

- Go over your insurance benefits
- Help you plan for your transplant costs before and after transplant
- Talk about other helpful resources

Bring your:

1. Insurance cards, prescription cards and insurance information
2. List of questions you want to ask
3. Transplant guide to take notes

Your financial coordinator helps in many ways. Your financial coordinator:

- Contacts your insurance company to find out exactly what your insurance plan pays
- Gets approvals from your insurance company for any medical services you need
- Confirms that you are covered for any needed clinic and hospital services

FINANCIAL COORDINATOR

Each person's situation is unique.
Talk to your financial coordinator about the best specific financial plan for your situation.

Use the time you spend with your financial coordinator to:

- Get more details about your specific transplant costs
- Understand what your insurance pays
- Be sure you are clear about what you pay
- Ask if you have questions or are not clear

Anything that has to do with money, bills and insurance can be confusing and stressful. When it comes to the money side of transplant, your goal is to make sure you are covered for any and all transplant-related costs.

Dealing with all of these money matters can be tough.
Ask questions. Plan ahead!

DO ALL YOU CAN TO WORRY LESS AND BE MORE AT EASE.

DOING MY FINANCIAL PART: PREPARE NOW

YES I CAN!

2 IMPORTANT THINGS FOR ME TO DO

1 KNOW WHAT TO EXPECT

☐ Costs related to transplant

☐ Type of insurance I have

☐ What my insurance pays and does not pay

☐ Costs I am expected to pay

☐ How much I pay and for how long

2 MAKE A FINANCIAL PLAN

☐ Meet with my Ochsner financial coordinator to get specifics about my transplant financial situation.

☐ Make a list of the resources available to me.

☐ Begin fundraising as soon as possible if needed.

☐ Know how I apply for assistance programs. Know what information I need to provide.

☐ Gather documents I may need to apply for assistance programs. These same documents can be useful in managing all transplant-related finances. Keep these documents handy in one place.

☐ Keep copies of all my important insurance and financial papers for my records.

☐ Keep a monthly written budget to better manage my finances.

☐ Get the best insurance coverage possible.

WHERE DOES THE MONEY GO?

Transplant costs include:

- Medicines, medical visits, tests and procedures you need before and after transplant
- Care you need before and after transplant
- Insurance deductibles and co-pay
- Travel, food and housing before, during and after transplant for:
    - You
    - Your caregivers

> "Don't agonize. Organize."
> – *Florynce Kennedy*

WHEN FINANCES ARE A CONCERN

Finances can cause a lot of stress and hardship for you and your family. Social workers are available to help as best they can. The time to talk about any financial concerns is before your transplant – even if it feels uncomfortable.

Your transplant social worker can help you:

- Handle any stress, worry or other feelings you may have if you are concerned about the financial side of transplant.
- Identify available options and resources. This helps you make the most informed decisions about your transplant and future goals.

PRIVATE COVERAGE	MEDICARE	MEDICAID
Insurance your job provides you or you buy on your own.	*Insurance the government provides.*	*State health insurance program that helps people with low incomes pay for some or all of their medical bills.*
Not all plans are the same. Know what medical services are covered and not covered. You pay whatever your insurance plan does not pay. Some insurance plans limit what they pay each year and/or in your lifetime. You pay any costs that go over this limit (cap). Ask for your plan's benefits booklet. Ask how your plan works when you have Medicare.	Available when a person turns 65 years old. People with certain permanent disabilities can get Medicare. Medicare stays in effect as long as you meet Social Security disability and Medicare guidelines. Your local Social Security office can help you with any specific questions.	Medical services and medicines that are covered vary from state to state, and year to year. Your Medicaid worker can help you know what your Medicaid pays.

IF YOU STILL HAVE UNANSWERED QUESTIONS ABOUT YOUR SPECIFIC COVERAGE:

Call your insurance company. Talk to your employer.

PLAN AHEAD

1. American Kidney Fund (AKF) insurance premium assistance ends at the time of transplant. Be prepared to pay for your insurance coverage after transplant.

2. If you get Medicare because of permanent kidney failure alone:
    - Your Medicare ends 36 months (three years) after the month you have a kidney transplant *unless* you have another qualifying disability.
    - Know exactly when your Medicare ends.
    - Plan ahead for how you will cover your transplant and other medical costs if your Medicare does end.

HELPS *to know*

CHANGES IN YOUR INSURANCE

Contact your financial coordinator ***right away*** if you have ***any*** changes with your insurance.

We want to make sure you:

- Still qualify for a transplant when your insurance changes
- Get the most from your insurance
- Spend the least amount possible on your out-of-pocket costs

If you choose to change your insurance company or coverage:

- Make sure you choose an insurance company and plan that covers all your transplant needs
- Talk with your transplant financial coordinator before you actually make any changes

INSURANCE COMMISSIONER'S OFFICE

Your state's insurance commissioner's office has a representative who can answer questions about:

- Available plans in your area
- Your insurance rights

MORE ON MEDICARE

Medicare Has 4 Different Parts

PART A

Pays in-hospital costs. Patient pays for deductibles and co-insurance.

PART B

Pays outpatient medical costs and may pay for some prescription medicines, like immunosuppressive medicines after transplant. Patient pays deductibles and co-insurance.

PART C

Part C is commonly known as Medicare Advantage. Several part C plans are available with different types of coverage.

Pays medical and prescription costs. Patient pays deductibles and co-insurance. Amount of deductibles and co-insurance varies depending on the specific plan.

All Medicare Advantage programs are run by private companies. Some part C plans pay for services from any provider. Other part C plans only pay for services by certain providers. Make sure Ochsner is a participating provider in the Part C program you choose.

PART D

Part D is often required for transplant patients depending on their other insurance coverage. Make sure you talk with your transplant financial coordinator about Part D.

Pays for some medicines. Patient pays deductibles, co-payments and co-insurance. Amount of deductibles and co-insurance varies depending on coverage that patient selects.

To be eligible for Part D, you need to:
- Be enrolled in either Part A or Part B
- Pay additional premiums and deductibles

Part D pays a certain amount for medicines each calendar year. Once you have spent this amount, you go into what is known as the donut hole. (See next section for more about the donut hole.)

UNDERSTANDING THE MEDICARE MAZE

Medicare can be confusing, especially when it comes to medicines. Ask your financial coordinator if anything about Medicare is unclear.

A few important points to keep in mind about Medicare:

- Medicare may cover certain medicines for life for people who get Social Security Disability Insurance (SSDI) or are over 65 years old.

- Medicare coverage alone does not cover all medical costs. You pay for whatever Medicare does not pay.

- Donut hole refers to the gap in what Part D pays after you have used the maximum amount to pay for medicines in that calendar year. Once you have spent the maximum amount offered by Part D, you pay for full costs of your medicines until you reach a certain limit.

  You may be able to get catastrophic coverage when you reach this limit. You only pay 5% of your medicine costs with catastrophic coverage. This cycle repeats every calendar year.

- Medigap plans pay Medicare deductibles and co-insurance. These are also known as supplemental F plans.

REMEMBER

There is a limited time frame in which you can get Medigap. We recommend you get a Medigap plan if you qualify and if this is a good option for your specific situation. Information is available at **www.medicare.gov.**

FOR THOSE WITH VETERANS AFFAIRS (VA) BENEFITS

- **Apply now** for any VA benefits.
- **Stay active** once you have VA benefits. You may have to be seen as often as your VA doctor recommends in order to stay active with the VA.
- **Follow up** with your VA doctor's recommendations. This helps make sure you have quicker access to your VA benefits after transplant.

NOTE: The Southeast Louisiana Healthcare System (formerly New Orleans VA) may serve patients more quickly if they are active in the local VA system.

PAYING FOR YOUR MEDICINES

Sometimes you may need financial help to pay for your medicines. Talk to your social worker or transplant coordinator right away if you are struggling to keep up with your medicine costs. There may be programs that can help.

PRESCRIPTION ASSISTANCE PROGRAMS (PAPS)

Some pharmaceutical companies have programs that help pay for medicines for people who qualify. Some PAPs may also help you pay for medicines when you are in the Medicare donut hole.

These Patient Assistance Programs (PAPs) may either:

- Give you medicine
  OR
- Help pay for your medicine co-pays after your insurance has paid

Each PAP has different guidelines for who qualifies. Some common factors that all PAPs look at to decide who can get help are:

- Income
- Insurance coverage
- Household size

REMEMBER

PAPs may or may not be an option for you. It depends on if you meet the PAP guidelines to qualify. This means you need to be prepared to pay for your medicines if no PAP help is available to you.

HELPS *to know*

Not taking your medicines after transplant can cause complications that result in organ failure and even death. The best thing you can do to keep your organ(s) and yourself healthy is to take all your medicines every day.

And that means being able to pay for your medicines! This is why it is so important for you to have the needed funds to pay for these medicines.

Be sure you understand what your insurance pays and what you pay. Ask if you have questions. You may need to fundraise before your transplant. Plan ahead!

Do not stop taking your transplant medicines because you do not have the money!

Call us to see if we can help you create a new plan.

FINANCIAL QUESTIONS TO ASK BEFORE TRANSPLANT

Here are some important questions to ask before your transplant surgery.

Bring these with you when you meet with your transplant financial coordinator.

- What is the average cost for a transplant, including care required before and after the transplant?

  ____

- What is the estimated cost for my transplant medicines?

  ____

- Do the costs vary if I have a living donor?

  ____

- Is treatment for my medical diagnosis covered?

  ____

- Is there a pre-existing clause for my plan? If so, what are the terms?

  ____

- Will my illness be considered a pre-existing condition?

  ____

- Will I have to pay for a portion of the costs? If so, about how much?

  ____

- Who will pay for my donor costs?

  ____

- What financial coverage does the hospital accept (Medicare, Medicaid, private insurance, etc.)?

  ____

- What can I do if my financial coverage runs out?

- Are there deductible and co-payment amounts? If yes, what are they?

- Does my plan cover expenses such as travel, food and lodging while I am at the transplant center? Will it cover these expenses for my family? How much will it pay?

- Will my insurance require pre-approval for any of my treatment?

Adapted from: www.transplantexperience.com/liver/support/finances/questions-to-ask

QUESTIONS TO ASK YOUR JOB BEFORE TRANSPLANT

- How long can I take off from work?

- Can I get short-term disability?

- Can I get long-term disability?

- If I am unable to work at some point, can I pay for COBRA (Consolidated Omnibus Budget Reconciliation Act) benefits?

- Can I get FMLA (Family Medical Leave Act)? (This question is for both patient and caregivers.)

RETURNING TO WORK AFTER TRANSPLANT

The goal of transplant is to improve your quality of life so you can lead a full, active life. You may decide to work after transplant. Returning to work after transplant may help you pay for your lifetime transplant costs. You may be able to get health insurance from your job. Health insurance from your job can help make sure you have ongoing insurance to pay for your medicines and other medical costs.

VOCATIONAL REHABILITATION

Your local Office of Vocational Rehabilitation can help with job training and job placement. This agency is aware of how working affects any disability benefits you get. They can help with the job training and job options that best fit your needs. Your social worker can help refer you to your local Office of Vocational Rehabilitation.

FUNDRAISING

Fundraising can be a useful way to help with transplant costs. Money from fundraising helps you have what you need for all expected and unexpected transplant costs before and after transplant.

Fundraising is often a major effort that requires help from your family, friends and even your community. It may be best to have a committee of volunteers to help you.

OTHER GROUPS THAT MAY BE ABLE TO HELP INCLUDE:

- Your church or religious organization
- Your job
- Groups you belong to
- Non-profit groups
- Local businesses
- Media (newspaper, radio, TV, social media)

YOU CAN RAISE FUNDS IN MANY WAYS. SOME IDEAS INCLUDE:

- Dinners
- Bake sales
- Raffles
- Car washes
- Garage sales
- Online social networking sites

These are just a few fundraising ideas.
There are many other ways to raise money. Ask others for ideas.
Be creative. Use your imagination!

REMEMBER

Talk to your:

- Transplant social worker or financial coordinator before you do any fundraising.
- CPA or accountant for specific advice.
- Bank about setting up a fundraising account. Show your bank the letter that says you are “listed for transplant.”

TRANSPLANT FINANCIAL SHEET

MONTHLY INCOME

Patient Take-Home Pay $__________

Spouse Take-Home Pay $__________

Social Security Income (SSI) $__________

Social Security (Disability) $__________

Military Pay/Veterans Pay $__________

Alimony/Child Support $__________

Rental Property/Real Estate $__________

Dividends/Interest/Investments $__________

Unemployment $__________

Food Stamps $__________

Odd Jobs (Cash only) $__________

Other Income (Not listed above) $__________

Total Monthly Income $__________

> "A year from now you may
> wish you had started today."
> – *Karen Lamb*

MONTHLY LIVING COSTS

Rent/Mortgage $__________

Electricity/Gas $__________

Water $__________

Phone/Cell Phone $__________

Cable/Internet/Satellite $__________

Groceries $__________

Eating Out/Restaurants $__________

Car Loan/Note $__________

Car Gasoline $__________

Car Maintenance $__________

Car Insurance $__________

Transportation (Bus, taxi, other) $__________

Medical Bills $__________

Health/Dental Insurance $__________

Life Insurance $__________

Homeowners/Renters Insurance $__________

Credit Card Payments $__________

(Add total if more than one) $__________

Education/Tuition $__________

Child Care $__________

Alimony/Child Support $__________

Personal Loan $__________

Other Costs (Not listed above) $__________

Total Monthly Living Costs $__________

ASK
myself

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

THE WAIT

Using my time wisely now that I am listed

NATIONAL TRANSPLANT WAITING LIST

You and your transplant team have agreed that you are ready to be placed on the waiting list for transplant. Right away your name goes on a national list of people waiting for a kidney and/or pancreas transplant. You are listed by your blood type. You, your doctor and your dialysis unit get written notice that you are now on the UNOS (United Network for Organ Sharing) waiting list.

> "Learn from yesterday, live for today, hope for tomorrow."
> – *Albert Einstein*

We want to know about changes in your life while you wait for your new organ(s). Always let us know if you have:

- A new address and/or phone number
- Any changes in your support system
- A new doctor and/or dialysis unit
- Started or stopped dialysis
- Been hospitalized or had surgery
- Had an infection
- Had a blood transfusion
- Been offered a kidney by someone
- Any insurance changes

It is especially important for you to stay in touch with us now that you are on the waiting list. Please make sure we know how to reach you at *all times*.

REMEMBER

We cannot transplant you if we cannot get in touch with you!

MULTIPLE LISTING

Multiple listing is being registered at more than one transplant center at the same time. Patients from transplant centers closer to the available deceased donor are usually considered before patients from more distant centers. This means multiple listing may:

- Increase your chances of getting a local offer
- Decrease your wait time by several months

In the state of Louisiana, you can only be on one transplant center's list. To be listed with other transplant centers outside of Louisiana, you must:

1. Contact each transplant center where you want to be evaluated
2. Be evaluated by the transplant center
3. Be accepted by the transplant center before you are registered on the UNOS list with this center

A few other points about multiple listing:

- Know the specifics about multiple listing if you decide to pursue this option.
- You may have other costs.
- Know your options for care after transplant.
- You can transfer your waiting time if you choose a different transplant center.

You are encouraged to call UNOS with any questions about multiple listing:
1-888-894-6361 www.unos.org

WHY EACH PERSON'S WAIT TIME IS DIFFERENT

"How long will I have to wait before I get my new kidney and/or pancreas?"

This is one of the most common questions we hear from patients on the transplant waiting list. Wait times are different for each person on the list because each person's situation is different.

The current average wait time for a deceased donor kidney in Louisiana is three to five years. The current average wait time in Louisiana for a deceased donor kidney-pancreas is one year. Your wait for a new kidney and/or pancreas may be as short as a few days or as long as several years.

Factors that *can* affect a person's wait time include:

- Blood type
- Tissue type
- Height and weight of the person
- Size of the donated organ(s)
- Antibody levels
- Crossmatch results
- Time on the waiting list
- Time on dialysis

Factors that *do not* affect a person's wait time:

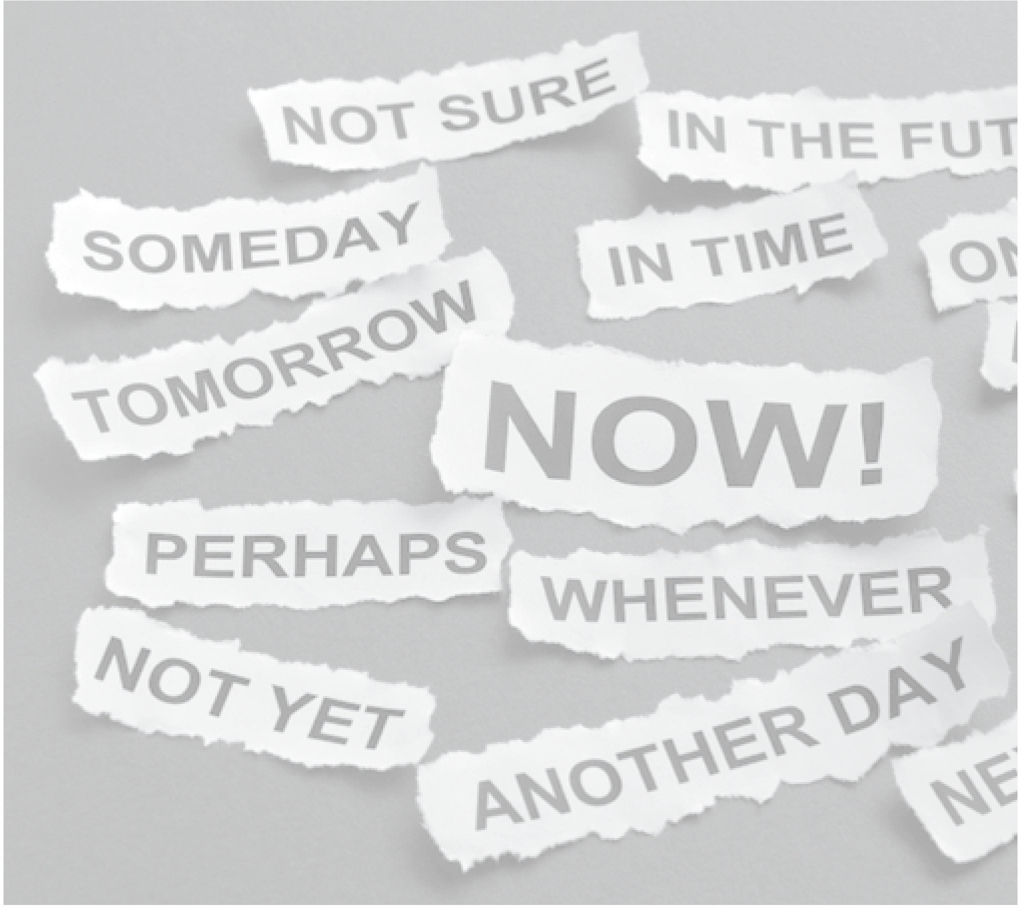
- Gender
- Race
- Religion
- Celebrity
- Financial status

A donated kidney and/or pancreas may look like a good match for you on paper. Your transplant surgeons do not know for sure until:

- Blood testing is completed
- They examine the organ(s) in person

You may not be transplanted if the surgeons decide this kidney and/or pancreas is not the best for you once they actually see the organ(s).

Unfortunately, there are more people on the transplant waiting list than there are available organs. This means it is impossible to know exactly how long you wait for the organ(s) that are the right match for you.



IMPORTANT FOLLOW-UP DURING YOUR WAIT

Make sure you keep up with needed care while you wait for a new organ(s):

1. All medical visits with your
    - a. Ochsner transplant team (yearly or semi-yearly)
    - b. Other doctors
2. Monthly blood samples

MONTHLY BLOOD SAMPLES

You send us one tube of blood each month while you are on the waiting list.

You can have your blood drawn by:

- Your dialysis unit if you are on dialysis

  OR
- An Ochsner facility

  OR
- Your local lab using tubes we mail to your home

We get monthly blood samples from you to:

- Check antibody levels in your blood
- Match your blood with a kidney and/or pancreas that may be right for you

---

You must come in to give us a blood sample if we do not have a recent sample. This can be at any time of the day or night.

Make sure you send us blood samples every month.
Sending us a monthly blood sample helps you:

- We can quickly test your blood when you are called.
- You save yourself a drive to Ochsner to give us a blood sample.
- You can usually wait at home while we test your blood.

YEARLY OR SEMI-YEARLY TRANSPLANT UPDATES

You come back to see us every six months to a year for updates:

- Transplant nephrologist or advanced practice provider to update your:
    - Medical history
    - Tests as needed
- Social worker to update your:
    - Personal history
    - Caregiver information

We send you a letter when it is time to make an appointment. Please call to make your appointment with us as soon as you receive this letter.

It is very important that you come back for these updates. You may not be able to be transplanted if your information is not up-to-date when you are called for a transplant.

EMOTIONAL SIDE OF WAITING

Being put on the transplant waiting list can comfort you and those close to you. You may feel more hopeful now that you are one important step closer to getting transplanted.

Waiting for your transplant can also be a difficult time. You may wonder why others get transplanted before you. Being called for a transplant and then not being transplanted can be tough for you and those close to you.

You may get frustrated while you wait. You may even feel depressed, anxious or helpless. It may help to talk openly with those around you about how all of you are feeling as you wait for your transplant.

Talk with your transplant team about any challenges you have while waiting for your transplant. We are here to support you and your caregivers during this time!

> "Everything comes gradually and at its appointed hour."
> – *Ovid*

HELPS *to know*

CaringBridge is a free, non-profit web service that connects family and friends to share information and support during a healthcare crisis, treatment and/or recovery.

You can get more information and sign up at:
www.caringbridge.org
651-789-2300

MY HOSPITAL CALL CHECKLIST

YES I CAN!

CONTACT INFORMATION

☐ My transplant team knows how to reach me at all times. I gave them all phone numbers to contact me right away when a kidney and/or pancreas become available.
☐ My transplant team knows when any of these phone numbers change.
☐ My cell phone is turned on, can be heard and is fully charged at all times.
☐ My transplant team's phone numbers are always with me.

PERSONAL/HOME ARRANGEMENTS

I have reliable people to:

☐ Care for my children and/or parents
☐ Watch my home
☐ Look after my pets
☐ Water my plants
☐ Pick up my mail (unless I have my mail held at the post office)
☐ Pay my bills (unless I choose to set up automatic bill payments)

RIDE TO THE HOSPITAL

☐ I have a primary driver who takes me to the hospital. My driver knows I have to leave for the hospital when the nurse coordinator tells me.
☐ I have a back-up driver in case my primary driver cannot drive me.
☐ My caregiver knows to travel with me to the hospital.

POINT PERSON

☐ I have someone to let others know how I am doing so I can get the rest I need while I am in the hospital.

PACKED BAGS

☐ For anyone staying with me in the hospital
☐ For myself

THINGS I WILL NEED IN THE HOSPITAL

YES I CAN!

- ☐ Medicines (prescription, over-the-counter medicines; injections if used)
- ☐ Medical equipment I use often
- ☐ Peritoneal dialysis (PD) supplies (if on PD)
- ☐ Eyeglasses (distance and reading)
- ☐ Underclothes
- ☐ Robe
- ☐ Slippers
- ☐ Socks
- ☐ Change of clothes
- ☐ Dental care items (toothbrush, toothpaste, dental floss; dentures if used)
- ☐ Hair care items (shampoo, comb, hairbrush)
- ☐ Deodorant
- ☐ Other personal care items
- ☐ Important phone numbers
- ☐ Personal transplant notebook
- ☐ Cell phone and charger*
- ☐ Identification*
- ☐ Cash *
- ☐ Credit card*
- ☐ Insurance cards*
    - ☐ Medicare card
    - ☐ Medicaid card
    - ☐ Private insurance card
- ☐ PAP application information* (if applicable)

Ask your caregivers to keep any valuable items for you so these do not get misplaced.

THINGS I MIGHT WANT TO HAVE TO BE MORE COMFORTABLE

- ☐ My own pillow, blanket
- ☐ Loose, comfortable clothing
- ☐ Reading material
- ☐ Crossword/jigsaw puzzles
- ☐ Laptop and charger
- ☐ Photos
- ☐ Paper and pen

DO NOT BRING

- ☐ Jewelry
- ☐ Other valuables that can be left at home

ASK *myself*

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

THE CALL

Time to go to the hospital

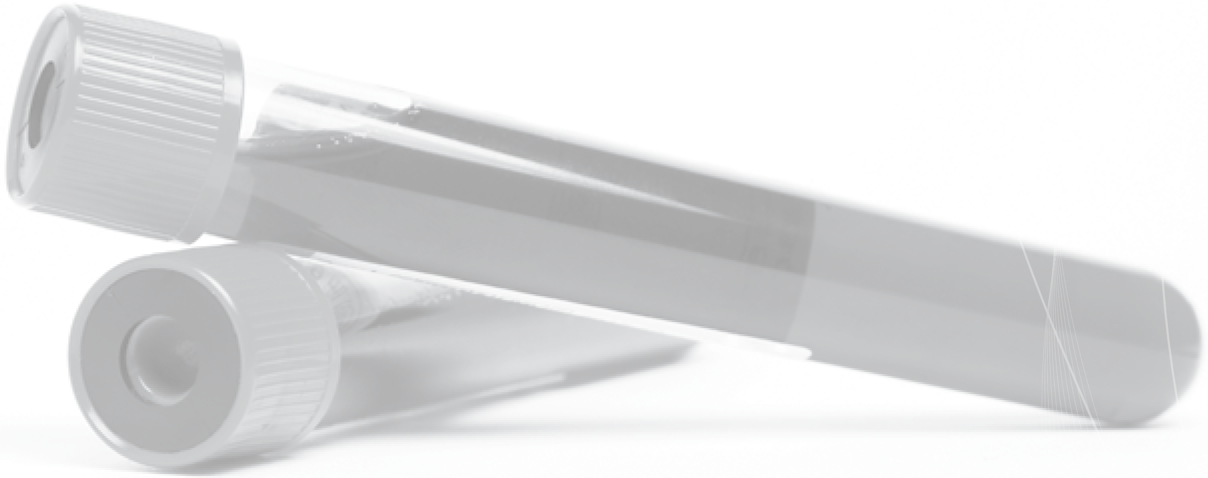
WHAT HAPPENS

- The transplant surgeon is offered a kidney and/or pancreas that looks right for you.

- The transplant nurse coordinator calls you to:
    - Let you know an organ(s) is available for you
    - Make sure you do not have any unknown medical problems

- If you have no medical problems:
    - We do a crossmatch test using your monthly blood sample and the donor's blood.
    OR
    - You drive to Ochsner to give us a blood sample if we do not have a current sample. We do a crossmatch test with this sample.

We turn down the organ(s) if we cannot reach you by phone after 60 minutes (1 hour). This is a national rule.



SAY *what?*

Crossmatch test is a test where blood from you and the donor are mixed.
This test shows if there is a reaction:

- No reaction: The donor's organ(s) can work for you. You are compatible with that donor.
- Reaction: The donor's organ(s) will not work for you. You are not compatible with that donor.

It takes about four to six hours to get crossmatch results. Your transplant coordinator tells you if you will wait for the results at home or at the hospital. Your transplant coordinator lets you know when to come to the hospital.

CALL AS BACKUP PERSON

You are called for a kidney and/or pancreas that looks right for you. Your nurse coordinator lets you know if you are the primary or backup person.

Primary person is the first person to be offered the organ(s). *Backup person* is the person on stand-by in case the primary person is not able to accept the organ(s).

Sometimes we find out at the last minute that the primary person cannot accept the organ(s). We always want to make sure available organs go to someone. That is why we have backup persons.

REMEMBER

You can be called as the backup person more than once and not get transplanted. This can be tough. You are still on the list. You may get transplanted next time!

INCREASED RISK DONOR

You may be told the new kidney and/or pancreas is from a deceased increased risk donor when you are called for transplant. An *increased risk donor* is a person thought to be at risk for spreading certain infections by the Public Health Service (PHS).

An increased risk donor may have:

- Had a blood transfusion
- Been in jail within the last 12 months
- Used IV drugs
- Had unsafe sex
- Taken part in other risky behavior as defined by the PHS
- Family who does not know the donor's history of possible risky behavior

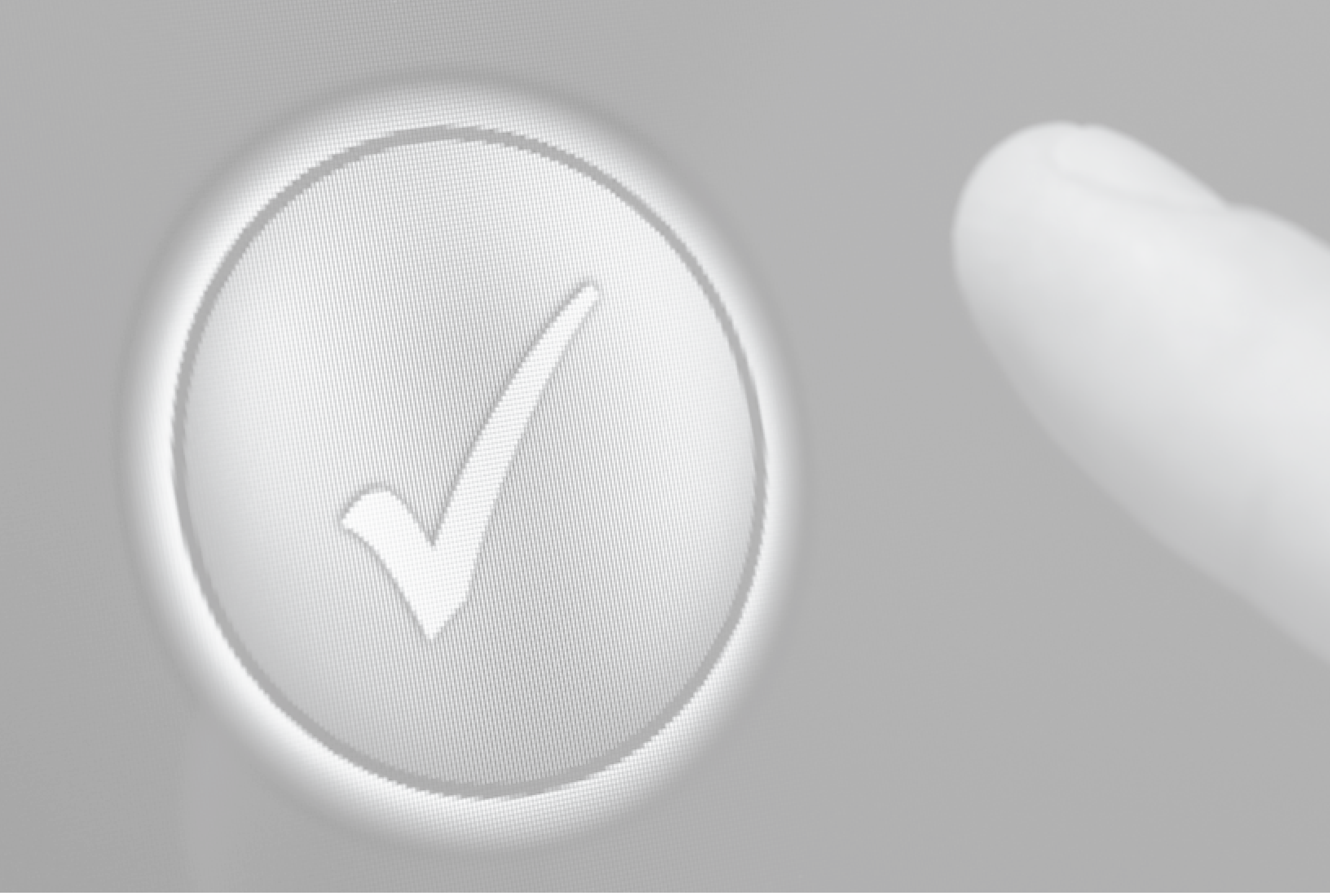
Increased risk donor lab tests are negative when the increased risk donor's organs are offered for transplant. There is a window of time (about 5-20 days, depending on the virus) when the donor could have been exposed to a virus. This means that even though the lab tests show up negative, the virus could be present. There is a small risk that you can get HIV or hepatitis if the donor's tests are false negatives.

You are told when the organ(s) being offered to you is from an increased risk donor. The transplant surgeon is happy to talk with you and your family if you have any questions.

Transplant surgeons review all donor information. You are only offered an increased risk organ if the surgeon thinks this organ will:

- Work well for you
- Benefit you

> "Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less."
>
> – *Marie Curie*



If you are offered an increased risk organ(s):

- You are told the behavior that makes this donor an increased risk donor.
- You choose whether you would like to accept this donor's organ(s).

You are not punished or removed from the transplant waiting list if you do not take this increased risk organ(s). You remain on the transplant waiting list at your present status.

REMEMBER

It is *your choice* to accept or not accept an organ from an increased risk donor. You decide! Keep in mind that the risk of dying from **NOT** receiving a transplant in time far outweighs the risk of getting an infection from a donor with increased risk behavior.

MATCHING AVAILABLE KIDNEYS WITH PATIENTS NEEDING KIDNEYS

Overview

- The goals are to:
  - Match kidneys that are most compatible with the patients needing a kidney
  - Use as many good kidneys as possible
  - Make sure every patient on the wait list has a fair and equal chance of getting a kidney

- Several factors are looked at when matching a donor kidney with a patient.

- Some groups of patients who need a kidney are hard to match with available kidneys. This can be because they have:
  - Blood type B
  - Highly active immune system

These groups of patients get added priority. This boosts their chances of getting a matching kidney.

SAY *what?*

Allocation means to give out or assign. Organ allocation is the system used to decide how deceased donor organs are matched with patients on the transplant waiting list.

HOW KIDNEYS ARE MATCHED

Two scores are used in matching kidneys. These are the KDPI score and EPTS score.
Let us take a closer look at how these scores are used.

	KDPI Score	**EPTS Score**
STANDS FOR	Kidney Donor Profile Index	Estimated Post-Transplant Survival
USED FOR	Deceased donor kidney	Patient needing a kidney
MEASURES	How long the kidney is expected to work	How long the patient is expected to need a working kidney transplant
SHOWN AS	Percentage that can be from 0 to 100 percent	Percentage that can be from 0 to 100 percent
LOOKS AT	Deceased donor • Height • Weight • Ethnicity • Brain or heart death • Stroke as cause of death • High blood pressure • Diabetes • Hepatitis C virus • Serum creatinine (measure of how kidney is working) • Age	Patient • Time on dialysis • Previous transplants (any organ) • Diabetes when listed for a transplant • Age

MATCHING PRIORITY

Kidney with KDPI equal to 20% or less ⟷ Patient with EPTS equal to 20% or less
Kidney with KDPI greater than 20% ⟷ Patient with EPTS greater than 20%

HARD-TO-MATCH PATIENTS

PATIENTS WITH BLOOD TYPE B

Patients with blood type B often wait longer for a kidney because blood type B donors are less common.

- Blood type B patients have the option to accept kidneys from type A donors with an A2 or A2B subtype.
- This means type B patients may get more kidney offers from blood type B, A2 and A2B donors.
- Type B patients get first priority for A2 or A2B kidneys.
- A special test is done to know if a patient with blood type B can be safely transplanted with an A2 or A2B donor's kidney.

PATIENTS WITH HIGHLY ACTIVE IMMUNE SYSTEMS

Some patients have a highly active immune system. This means they produce antibodies that may cause them to reject a kidney transplant. These patients are called *highly sensitized* patients.

Fewer kidneys are a good match for highly sensitized patients. Highly sensitized patients get more priority for kidneys that are a good match for them. This boosts their chances of getting kidney offers.

Your transplant team tells you:
- If you are highly sensitized
- Extra priority you get for matching kidneys if you are highly sensitized

GETTING LISTED FOR KIDNEY TRANSPLANT AS SOON AS POSSIBLE

The best time to get evaluated and listed by a transplant center for a kidney transplant is:

- Before you start dialysis (GFR is 20ml/minute or less)

  OR

- When you start long-term dialysis

This lets you be considered as early as possible for a kidney transplant.

WAIT TIME ONCE LISTED FOR KIDNEY TRANSPLANT

How long a patient is on the transplant waiting list is an important part of how kidneys are offered to patients needing kidneys. Patients begin earning wait time points when listed once:

- GFR is 20 ml/minute or less

  OR

- On dialysis – with credit for time on dialysis before listing

QUALIFYING FOR KIDNEY-PANCREAS TRANSPLANT

You must have:

- Kidney failure
- Diabetes

You begin earning waiting time as soon as you:

- Are registered for a kidney-pancreas transplant
- Meet the guidelines to earn kidney waiting time (See Wait Time Once Listed for Kidney Transplant.)
- Meet the guidelines for a kidney-pancreas transplant:

C-Peptide	BMI	Insulin
C-peptide is less than 2 ng/mL	BMI must be less than or equal to 30	Actively on insulin
C-peptide is greater than 2 ng/mL	BMI must be less than or equal to 28	Actively on insulin

SAY *what?*

Insulin C-peptide test measures the amount of C-peptide in your blood. This test helps:

- Know how much insulin your pancreas makes
- Tell if you have type 1 or type 2 diabetes

HELPS *to know*

Directed Donation

Directed donation is when a donor or donor family asks for a specific person to get the donor's organ(s). If a donor asks that his or her organ(s) be directed to you:

1. Donor family contacts LOPA
2. You contact Ochsner transplant coordinator

YES I CAN!

I HAVE FINISHED TALKING TO THE NURSE COORDINATOR ABOUT COMING INTO THE HOSPITAL.

Now I make sure I:

☐ Leave for the hospital when the nurse coordinator tells me.
Note: For peritoneal dialysis (PD) patients: Drain my PD fluid as my coordinator instructs me to drain. Bring enough PD supplies for three to four exchanges.
☐ Have my caregiver with me when I travel to the hospital
☐ Ask my coordinator what I can eat or drink
☐ Have everything I need to take with me to the hospital
☐ Have taken care of anything that needs to be handled for me while I am in the hospital
☐ Park in Ochsner's parking garage – the same garage where I park for my medical visits before transplant
☐ Have my caregiver with me in the hospital
☐ Go straight to the Admit Office on the first floor
(Monday-Friday, 8am-5pm)
OR
Go straight to the Emergency Room
(Monday-Friday, 5pm-8am; weekends)

Once you get to the hospital, you will be told what to do next.

Hold up – Did I remember everything?

☐ Do I know where to go once I get to the hospital?
☐ Do I have my packed bags with me?
☐ Did I make all arrangements for while I am in the hospital?

ASK *myself*

1.

What do I need to do?

2.

What do I need to remember?

3.

Why is it important?

THE HOSPITAL STAY

What to expect during my stay

BRIEF LOOK AT WHAT HAPPENS DURING YOUR HOSPITAL STAY

You go to your hospital room once you are admitted. Below is a brief overview of what happens before, during and after your surgery. You are given more detailed information in the hospital.

BEFORE SURGERY

- You are told more about your transplant surgery and hospital stay.
- You are prepared for the transplant surgery:
  - Brief exam
  - Chest x-ray
  - Lab testing
  - EKG
- You get anesthesia to make you sleep.
- Transplant surgeons prepare the new organ(s) for transplant.

Kidney surgery takes about two to four hours.
Kidney-pancreas surgery takes about four to five hours.

DURING SURGERY

- Curved cut is made in the lower side of your abdomen for a kidney transplant. Vertical cut is made in the center of your abdomen for a kidney-pancreas transplant.
- New organ(s) is attached to blood vessels in your groin area.
- Blood is able to flow to your new organ(s). Most new organs begin to work very quickly.
- Tube that connects your kidney and bladder (ureter) is attached to your bladder.
- Small plastic tube (stent) is put in the ureter to allow healing and prevent narrowing of the ureter.
- Kidneys and/or pancreas you were born with are usually left in place. They are only removed in special cases. Your doctor will let you know during your work-up if yours is a special case.
- Tubes are placed to drain fluid from the area. These are usually removed several days later.
- Your cut is closed using special stitches and staples. The inside stitches will dissolve. The staples are removed in clinic about three weeks after surgery.

Your family and friends wait for you in the surgery waiting room while you are in surgery.

It is hard to know *exactly* how long your surgery takes. Your surgeon keeps your family informed during your surgery.

SAY *what?*

Abdomen is another word for belly. It is the area between your chest and hips. Your digestive organs are housed here.

WHAT YOU SEE WHEN YOU WAKE UP AFTER SURGERY

It may be scary to see tubes and drains in you if you do not know what they are for. It may help put you at ease if you know what to expect:

- **Drains** are placed near your cut. These drains remove any extra fluid that may build up inside the cut. These drains are taken out once the amount of fluid drained is low and your surgeon feels it is safe.
- **Tubes** are placed in your:
    - **Bladder** to allow for healing where the ureter and bladder are connected. This tube is called a catheter. The catheter is removed once the surgeon feels it is safe in three to seven days after surgery.
    - **Nose, down into your stomach** – ONLY for combined kidney-pancreas transplant patients. This tube drains anything in your stomach. Tube is removed once your stomach and bowel begin working.
- **IV drips** for fluids and pain medicine are placed in the side of your neck and arm.

POSSIBLE COMPLICATIONS

Complications are possible with any surgery. You may stay in the hospital longer if you do have complications.

Your transplant team watches you closely for any complications. Some examples of complications are:

- Fever
- Bleeding/clotting problems
- Sleepy kidney or pancreas
- Infection
- Rejection
- Fluid problems
- Kidney disease reappears
- Loss of new organ(s)
- Death

HELPS *to know*

Sleepy kidney or pancreas: Your newly transplanted organ(s) may not work right away. You may need dialysis or insulin treatments after transplant until the new organ "wakes up." Delayed kidney or pancreas function is usually temporary. It happens in about 10-20% of patients.

Infection: The medicines you take after transplant lower your ability to fight infection. It is easier for you to get infections. Some examples of infections are pneumonia, CMV (cytomegalovirus) and wound, urine and fungal infections. We give you medicines to help your body resist infections.

Rejection: Your body sees your new organ(s) as not belonging to you. Sometimes it tries to get rid of (reject) your new organ(s). Rejection is most likely to happen in the first three months after transplant. We treat rejections with medicines. Most rejections are treated successfully. About 7-10% of patients have at least one rejection episode in their first year after transplant.

Fluid problems: Fluid can collect around your new organ(s). You may have urine leaks or draining around your wound.

Kidney disease reappears: The disease that damaged your own kidney can reappear in your new kidney. Some kidney diseases have a greater chance of returning after transplant.

Loss of new organ(s): Very rarely occurs

Death: Very rarely occurs

HOSPITAL STAY AFTER TRANSPLANT

After your surgery, you are taken to:

- Transplant Stepdown Unit (TSU) if you got a kidney.
- Intensive Care Unit (ICU) for one to two days if you got a kidney and pancreas. You are moved to TSU once you are stable.

Patients are usually in the hospital for:

- Two days for a kidney transplant. Time in the hospital depends on how your kidney is working.
- Five to seven days for a kidney-pancreas transplant.

You may stay longer depending on your specific medical condition.
Your transplant team talks with you about how long you stay in the hospital.

> “Do not let what you cannot do interfere with what you can do.”
>
> – *John Wooden*

RECOVERY

Most patients start to walk within one day of surgery. Patients begin eating once medically stable. You may be surprised at how much better and stronger you feel each day with your new working organ(s).

We do regular testing while you are in the hospital. We draw your blood often so we know your organ(s) works well.

We tell you and your caregiver what you need to do while you are in the hospital to care for yourself.

We teach you and your caregiver how to:

- Keep track of your vital signs (temperature, pulse, blood pressure)
- Manage your pain
- Know what and when to eat
- Know what and how much activity is good for you
- Take your medicine the right way, at the right time

KIDNEY 2-DAY TRANSPLANT ROAD TO RECOVERY

	TRANSPLANT DAY	DAY 1 AFTER TRANSPLANT	DAY 2 AFTER TRANSPLANT
My Nurse Checks	• Vital signs • Urine • Incision	• Vital signs • Urine • Incision	• Vital signs • Urine • Incision
For Pain, I	• Use my IV pump for pain medicine • Rate my pain from 1-10	• Take pain medicine by mouth • Call my nurse for pain medicine	• Take pain medicine by mouth • Call my nurse for pain medicine
I Make Sure I	• Drink clear liquids • Rest in bed • Have someone stay with me after I leave the hospital	• Eat my meals • Drink 2 liters of water • Sit in a chair 3 or more times	• Eat my meals • Drink 2 liters of water • Walk with help 3 times
I Learn How To	• Read my transplant binder • Take my medicines using the Blue Card	• Clean my incision • Take my medicines • Measure the liquids I drink • Measure my urine • Take my vital signs	• Read my transplant binder • Clean my incision • Take my medicines • Measure liquids I drink • Measure my urine • Use my home supplies • Get my labs and see the doctors after I leave the hospital • Take my vital signs

KIDNEY-PANCREAS 7-DAY TRANSPLANT ROAD TO RECOVERY

	TRANSPLANT DAY	DAYS 1 & 2 AFTER TRANSPLANT	DAYS 3-7 AFTER TRANSPLANT
My Nurse Checks	• Vital signs • Urine • Incision • Tubes • Blood sugar	• Vital signs • Urine • Incision • Tubes • Blood sugar	• Vital signs • Urine • Incision • Tubes • Blood sugar
For Pain, I	• Use my IV pump for pain medicine • Rate my pain from 1-10	• Use my IV pump for pain medicine • Rate my pain from 1-10	• Take pain medicine by mouth • Call my nurse for pain medicine • Rate my pain from 1-10
I Make Sure I	• Rest in bed • Talk with my medical team	• Sit in a chair with nurse's help 1 to 3 times • Talk with my medical team	• Eat my meals • Drink 2 liters of water • Walk with help 3 times
I Learn How To		• Read my transplant binder	• Read my transplant binder • Clean my incision • Take my medicines • Measure liquids I drink • Measure my urine • Use my home supplies • Get my labs and see the doctors after I leave the hospital • Take my vital signs

PREPARING TO LEAVE THE HOSPITAL

YOUR LEARNING

We teach you how to best care for yourself after you leave the hospital. We go over your transplant binder with you. This binder is yours to keep after you leave the hospital.

YOUR PLANNING

Your transplant social worker meets with you in the hospital to make sure that after you leave the hospital, you have:

- Reliable caregivers after transplant
- Place to stay, both short-term and long-term
- Transportation on the day you leave the hospital
- Transportation to your follow-up medical visits, labs and tests after transplant
- Place and way to buy your medicines
- Medical equipment you might need
- Extra needed support, like home health or physical therapy
- Any other support you might need

SAY *what?*

DISCHARGE

Discharge is when you leave the hospital. *Discharge plan* is the plan for you after you leave the hospital. You and your healthcare team review the plan while you are still in the hospital.

Some things in your plan are for all transplant patients. Other things are just for you. We want to make sure we plan ahead to meet your needs. Now is the time to let us know of any concerns you have about your needs after transplant!

ASK
myself

1.
What do I need to do?

2.
What do I need to remember?

3.
Why is it important?

LIFE AFTER TRANSPLANT:

Brief Look Ahead to Life with a New Organ(s)

PREPARING FOR LIFE WITH A NEW KIDNEY AND/OR PANCREAS

You may ask: "Why not wait until I get transplanted to talk about life after transplant?"

The answer: Patients tend to do better after transplant when they prepare before transplant! Patients are better able to care for themselves and their new organ(s) when they know before transplant what to expect after transplant.

Let us take a look at what life after transplant means for you. We want you to understand three key points about life with a new organ(s).

> "What you do every day matters more than what you do once in awhile."
> – *Gretchen Rubin*

3 KEY POINTS TO UNDERSTAND NOW

1 YOU MAKE A LIFETIME COMMITMENT

Taking good care of yourself after transplant means doing your part to care for your new organ(s) and yourself – for life.

YOU AGREE TO:

- Take care of your incision
- Track certain body signs
- Know your healthcare team
- Follow your healthcare team's advice
- Show up for all medical visits, labs and tests
- Let us know if you feel depressed, anxious or helpless

2 YOU AVOID INFECTION AND REJECTION

Infection and rejection are the two main possible complications after transplant.

YOU AGREE TO:

- Take needed action to avoid infections
- Take your anti-rejection medicines as instructed – every time, on time
- Follow instructions on how to care for yourself

3 YOU MAKE NEEDED LIFESTYLE CHANGES

Most patients are able to live a pretty normal life after transplant. You may need to make some changes with a new organ(s).

YOU AGREE TO:

- Practice healthy habits
- Wait until your wound is healed before having sex after transplant
- Get your doctor's okay before getting pregnant (women)

1. LIFETIME COMMITMENT

TAKE CARE OF YOUR INCISION

All your incision usually needs after you leave the hospital is daily washing of the skin. You want to avoid soaking in the bathtub, hot tub or pool if your incision has a scab. Let your transplant team know right away if there is anything unusual with your incision.

TRACK CERTAIN BODY SIGNS

You write down certain body signs in your transplant binder every day for twelve weeks after your transplant. We review your results at your clinic visits. These body signs help us know if:

- You and your new organ(s) are healthy
- We need to adjust your medicines

KNOW YOUR HEALTHCARE TEAM

You are followed by the transplant team for life. Other doctors also take care of you after transplant. You see different doctors for different reasons. Know who to call and for what. Write their names and information in your transplant binder.

FOLLOW YOUR HEALTHCARE TEAM’S ADVICE

Listen carefully to your healthcare team’s advice. Follow what they recommend. Ask when you are not sure or need more information.

SHOW UP FOR ALL MEDICAL VISITS, LABS AND TESTS

Medical visits, labs and tests are how we best monitor you. They let us know if you and your new organ(s) are doing well. It is very important that you come to all of your medical appointments as scheduled.

We see you more often when you first get out of the hospital, especially for the first month after transplant. You have fewer medical visits and labs over time as long as you are doing well. How often you have medical visits and labs after transplant depends on your unique circumstances.

Expect to stay in New Orleans for at least two to four weeks after transplant if you are from out-of-town. We want to make sure you are stable enough before leaving New Orleans. You are followed by your local doctor and have your labs done locally once you are able to leave New Orleans.

LET US KNOW IF YOU FEEL DEPRESSED, ANXIOUS OR HELPLESS

Talk to your transplant team about any challenges you have after transplant. We are here to support you and your caregivers during this time!

> “Obstacles are those frightful things you see when you take your eyes off your goal.”
>
> – *Henry James*

2. INFECTION AND REJECTION

TAKE NEEDED ACTION TO AVOID INFECTIONS

The medicines you take after transplant for the rest of your life lower your ability to fight infection. It is easier for you to get infections. You can catch colds more easily. Your cuts and scratches can more easily become infected.

You can still go out and enjoy your life. Just take the needed action to avoid infections after transplant. You are given a complete list of these actions after transplant.

This includes making sure you always:

- Wash your hands right away after you eat or use the bathroom
- Avoid eating or drinking someone else's food or drink
- Avoid close contact with anyone who has a bad cold, flu or other disease you can catch like the measles, chickenpox or shingles
- Get your needed shots each year
- Have your pets get their yearly shots
- Tell us right away if you have any signs or symptoms of infection

TAKE YOUR ANTI-REJECTION MEDICINES AS INSTRUCTED – EVERY TIME, ON TIME

These medicines help keep your body from attacking or rejecting your new organ(s).

You ***must*** take theses medicines for the ***life of your new organ(s).***

Never miss even one dose or change your dose unless your transplant team tells you to do so. Rejection can happen any time – especially if you stop taking your anti-rejection medicines on your own or sometimes forget to take them.

Almost all transplant patients have at least one rejection episode at some time. Rejection is most likely to happen in the first three months after transplant.

Your labs give us the earliest sign of rejection – even before you look or feel bad. These labs tell us how your new organ(s) is working. This is why it is so important to get your labs done as scheduled!

We treat rejection with medicines. Usually we can treat rejection without you having to be in the hospital. Sometimes you may need to stay in the hospital.

HELPS *to know*

Many people experience side effects from their anti-rejection medicines. Some of the most common side effects are:

- Anxiety
- Diarrhea
- Headache
- Nausea/vomiting
- Shaking
- Swelling of feet, hands, belly
- High blood pressure
- Higher blood sugar

Let us know right away if you have any of these symptoms. We can help you manage any side effects.

The most commonly used anti-rejection medicines include:

- CellCept (Mycophenolate Mofetil) or Myfortic
- Prograf (Tacrolimus)
- Steroids (Prednisone)

PRACTICE HEALTHY HABITS

You want to stay as healthy and active as possible.

A few reminders:

- Exercise
- Rest
- Only use drugs and alcohol that your doctor okays
- Do not use tobacco
- Watch your weight
- See your dentist twice a year
- Use sunscreen
- Have your yearly check-ups and screenings

WAIT UNTIL YOUR WOUND IS HEALED BEFORE HAVING SEX AFTER TRANSPLANT

Your wound is usually healed in four to six weeks after transplant. There are no restrictions to positions or frequency of sexual activity once you have sex again. Practice safe sex to prevent sexually transmitted diseases (STDs). Talk openly with your transplant team about these matters. It is important for your health.

GET YOUR DOCTOR'S OKAY BEFORE GETTING PREGNANT (WOMEN)

Talk to your transplant team about your personal situation if you are planning to get pregnant.

- Wait at least one year after transplant before getting pregnant.
- Use birth control to prevent getting pregnant during this time. Check with your doctor before starting birth control.
- Be aware that some transplant medicines can cause birth defects.

SAY *what?*

Your body tries to get rid of anything that it thinks does not belong inside you, like a new organ(s). It wants to keep you safe from danger.

This is what is known as your ***immune system*** – a fancy way to describe your body's system that keeps you safe from illness and disease. This is great for things like a cold or flu. We just do not want your body to attack your new organ(s).

We give you medicines to prevent your body from attacking your new organ(s). These medicines are called ***anti-rejection medicines*** – medicines that stop your body from getting rid of *(rejecting)* your new organ(s). They are also called ***immunosuppressive medicines*** – medicines that lower *(suppress)* your body's desire to attack your new organ(s) in order to keep you safe *(immune)*.

GETTING IN TOUCH WITH YOUR DONOR FAMILY

People who get a new kidney and/or pancreas often want to write their donor family. A card or letter from you can be a special gesture for your donor family. Keep in mind that your donor's family may or may not write back.

Talk to your transplant social worker if you want to get in touch with your donor family. He or she can give you more detailed information.

ASK *myself*

1.

What do I need to do?

2.

What do I need to remember?

3.

Why is it important?

NOTES

NOTES

NOTES

NOTES

Ochsner™
Multi-Organ Transplant Institute

504.842.3925 or 800.643.1635
ochsner.org/transplant